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TITLE: Building a Better Model: A Personalized Breast Cancer Risk Model
Incorporating Breast Density to Stratify Risk and Improve Application of Resources

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BC100474: Building a Better Model: A Personalized Breast Cancer Risk Model Incorporating Breast Density to Stratify Risk and Improve Application of Resources

INTRODUCTION:

This project is aimed at meeting informational needs by moving the nation from guidelines based on population averages to recommendations based on an individual's risk beginning with personalized mammography screening decisions. This will be done by increasing the ability to predict a women's risk of developing breast cancer by adding a strong risk factor—breast density—to current risk-assessment equations or algorithms. Our plan is, over three years, to build and initially validate a comprehensive breast cancer risk model. The overall work will require the recruitment of 1000 cases (breast cancer patients) and 3000 controls (non-breast cancer patients) from whom we will collect extensive risk factor information and breast density based on digital mammograms previously obtained at UVa. Breast cancer risk information is largely already available for cases though patients will be requested to validate and complete data. The recruitment of 3000 control patients will require engagement with the community through appropriate messaging and marketing. The measurement of breast density using automated methods will be optimized during this study through the evaluation of outlier correction, comparison of several different software methods, precision measurement, and evaluation of variation by mammography machine vendor. Once the model is complete, tested nationally, and proven accurate, it will be available for widespread use within five to six years.

BODY:

Research accomplishments are listed by Task.

Task 1: Develop procedures for team communication and coordination (month 1)

Completed. A listserv was developed for the group early on. Bi-weekly conference calls are held on Tuesdays at noon. An agenda precedes the call by at least one day. Quarterly Team meetings have been held at UVa (12 Dec 2011, 16 March 2012, 05 June 2011, 4 Dec 2012, March 8, June 17, planned 09 December 2013). Bi-annual team meetings have been held, alternating at UVa (09 Sept 2011, 24 Sep 2012, 23 Sep 2013) and Toronto (20 April 2012, 03 May 2013). All PIs, advocates, and key personnel attended these meetings.

Task 2: Submit protocol to Institutional Review Board/Human Investigation Committee (months 1-3)

Completed. Study protocol, consent, and recruitment materials were drafted, submitted to UVa IRB and to DoD for review. All have been approved. The UVa IRB reviews all open protocols and consent forms annually; once approval has been received locally (anticipated in early November), the updated documents were approved by DoD.

Task 3: Establish secure database (months 1-2)

Completed. A secure database has been established behind a secure firewall. The database is HIPAA compliant. Data fields and dictionary were defined. Minor changes

were made to clarify choices. Data linkages have been validated. Data has been successfully extracted with a small number of unanswered items. These primarily relate to details about breast cancer diagnosis (histologic type, grade, etc.). These data are being entered using our Breast Cancer Database and Clinical Data Repository in an ongoing fashion.

Task 4: Perform outlier correction for 3D Cumulus (CumulusV) (months 2-6)

The first round of outlier correction was completed during Year 1. Cumulus V was used to analyze a set of 260 mammograms for volumetric density, and those results were compared with estimations of area density made by Dr. Harvey using our two-dimensional Cumulus 2D area method. During a work visit to Toronto from October 29 to November 3, 2011 Dr. Harvey evaluated any discordant readings using color maps to visually correlate the density map with the mammographic image. In January 2012, Olivier Alonzo-Proulx performed the calibration of the seven mammography units of UVA, including three units at the Breast Care Center, three units at the Northridge site including the mobile clinic and one system at Orange Medical Center. Both the detectors and the thickness readout mechanisms were characterized on each of the units in order to make retrospective and prospective volumetric breast density measurements.

Further modifications were made to the density algorithm and the images were reevaluated. The new data were reviewed during Dr. Harvey's visit to Toronto (16 Apr to 20 Apr 2012). Some results are shown in Figure 1 and demonstrate an improved correlation between the gold standard Cumulus 2D and CumulusV. Correlations were also made using Volpara, a commercially available volumetric density measurement tool. Some results are shown in Figure 2 where the correlation between the two algorithms is seen to be quite high. The Volpara measurement systematically indicates lower volume, since it excludes the contribution of skin.

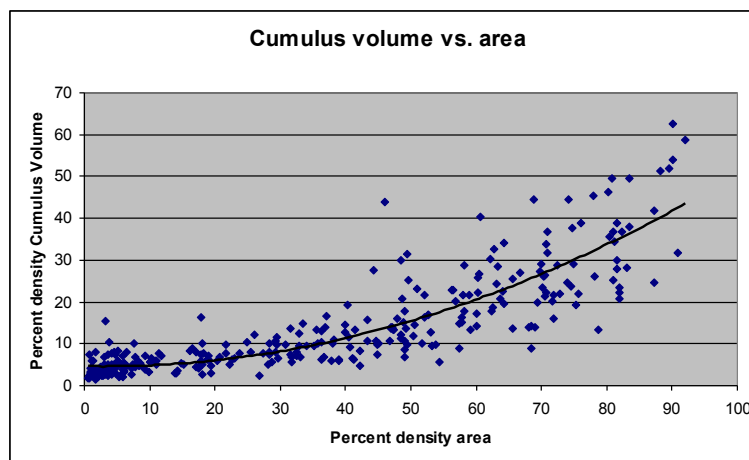


Figure 1: Cumulus 2D area (measured by Dr. Harvey) density vs. Cumulus V volume. The quadratic correlation is $R = 0.87$.

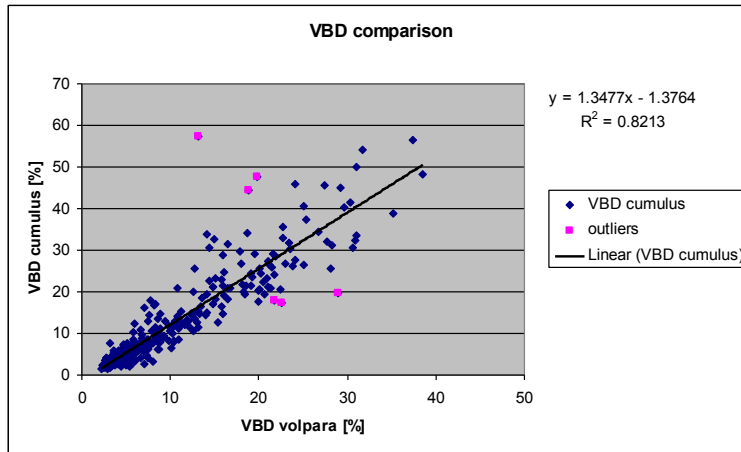


Figure 2: Cumulus volume vs. Volpara volume

A limitation of the above dataset is the fact that the mammograms were acquired over a long period of time, during which the machines may have been serviced or altered. Several detectors have been replaced since those images were obtained and this may have resulted in the calibration not representing the actual state of the imaging system at the time that the mammograms were acquired.

Second dataset. To test CumulusV using more recent mammograms, a new dataset was collected and retesting was completed during Year 2. The new dataset included 100 images from a GE unit and 100 images from a Hologic unit. These were reviewed during Dr. Harvey's visit to Toronto October 2012. The three volumetric methods (CumulusV, Volpara, Quantra) were compared to the gold standard area based method, Cumulus 2D (Figures 3-5). Volpara had the best correlation.

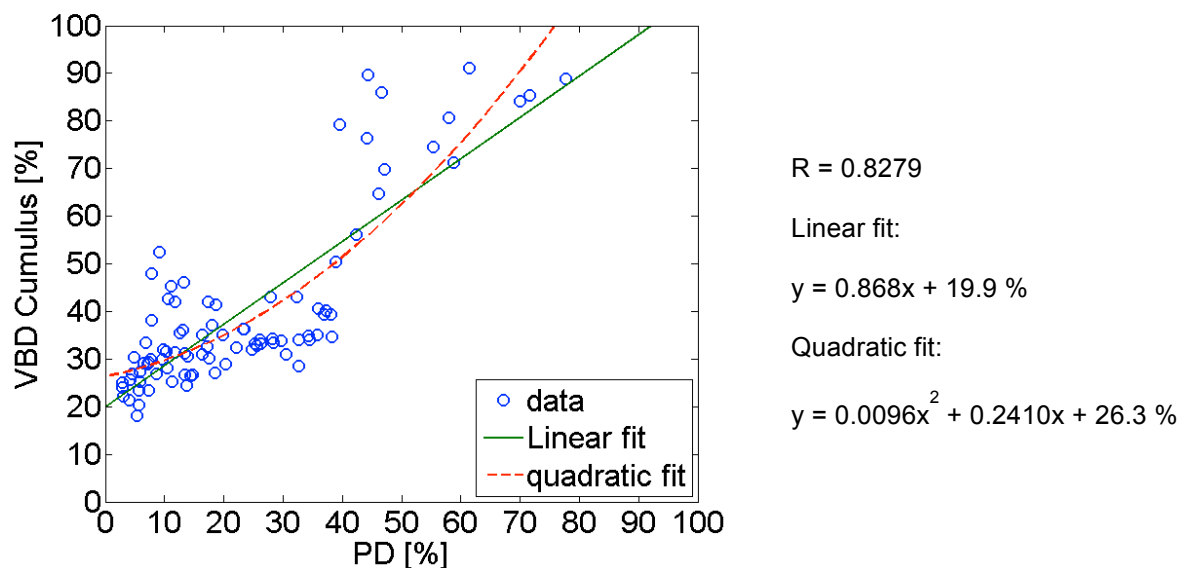


Figure 3. CumulusV density measures compared with Cumulus 2D (area) method. There is not a marked difference between the new dataset and the prior.

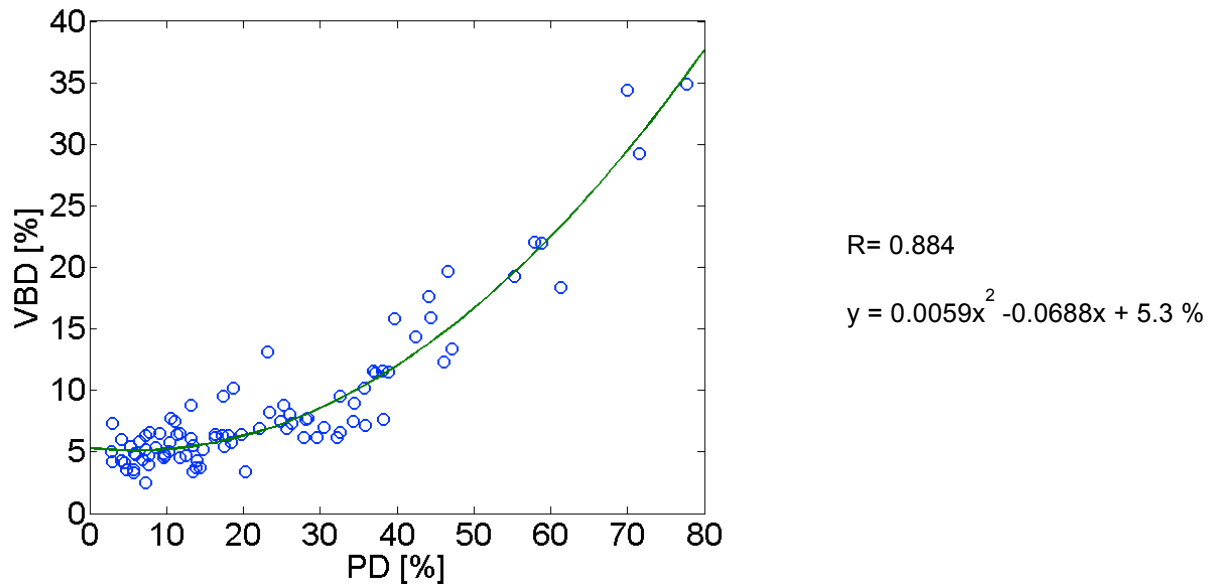


Figure 4. Volpara density measurements compared with Cumulus 2D (area). This method has strongest correlation with the area based method with an R value of 0.884.

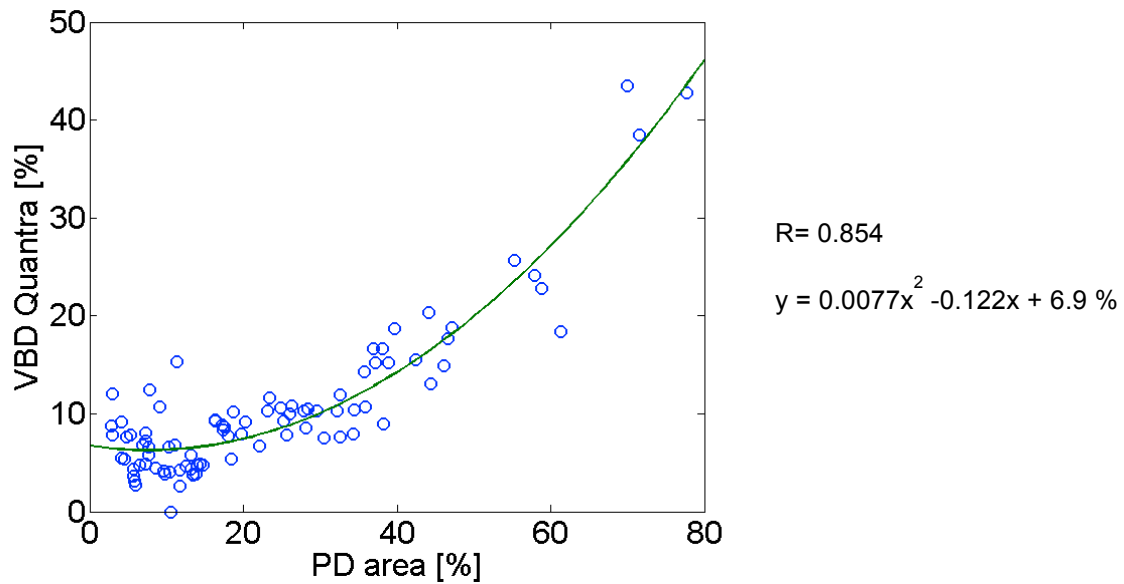


Figure 5. Quantra density measurement compared with Cumulus 2D (area). This method had good correlation with the area based measurement.

Task 5: Populate and validate database with existing data (months 3-6; may need to be adjusted based on IRB approval date) HARVEY

Completed

5a. Link existing radiology data sets with Clinical Data Repository (month 3-4). Our current breast cancer database is Microsoft Access format. The entries, while clear to us, are variable in style. For example, the term half-sister may have been entered as "half-sister," "half sister," or "1/2 sister." These variables reduce the accuracy of prepopulation of our database very challenging and with many errors. Because of this, we will use the database to obtain information about our case patients prior to their arrival to clinic that can be used to help patients complete the form. In addition, information that is missing or answered "I don't know" will be completed using the existing database (many patients do not know specific details about their breast cancer).

5b. Identify missing data that can be obtained via chart review (month 3-4). This will be an ongoing process as cancer case patients complete their survey. For case patients that are no longer in the area or have passed away, we will populate the information using both the MS Access database and chart review.

5c. Conduct chart review for selected cases (month 4-6). Comparison of information from the Breast Cancer Database and medical records showed good consistency (for example, details of treatment for cancer cases were the same between sources). Both sources will be used to help fill in missing data prospectively.

Task 6: Case ascertainment (month 6) KNAUS

6a. Apply inclusion/exclusion criteria to populated database (month 6).

6b. Date of diagnosis and age identification for matching with controls (month 6).

6c. Identify specific missing data fields that can be obtained by interview (month 6).

Completed. Case ascertainment was performed using a combination of our Clinical Data Repository and our MS Access Database. Over 2000 eligible cases were identified.

Task 7: Control ascertainment (month 7) KNAUS

7a. Apply inclusion/exclusion criteria to potential controls (month 7)

7b. Match to cases within five years of diagnosis of breast cancer (month 7).

7c. Identify up to 15 potential controls for each case (month 7)

Completed. Over 28,000 potential control patients have been identified. The cases and potential controls are contained in a MS Excel spreadsheet so that when a patient presents to the clinic, the research staff can easily see if she qualifies for the study.

Task 8: Develop Automated 2D Cumulus program (months 7-12) YAFFE

8a. Create a volumetric composition map using 3D Cumulus on Dr. Harvey's previously validated 340 mammogram dataset (months 7-9)

8b. Perform quasi-2D density analysis on dataset maps (month 10).

8c. Optimize algorithm during Dr. Harvey's visit to Toronto (month 11)

Completed. The current 2D method of Cumulus has a well validated association with breast cancer risk. However this method is labor intensive and used only in research. Because 2D methods of measuring breast density are not dependent upon having accurate measurements of breast thickness, an automated 2D Cumulus measurement may prove more reliable than 3D methods. Dr. Yaffe's group has developed an automated 2D method. Figure 7 shows the automated 2D (area) results on the same dataset presented in Task 4 (figures 1 and 2). The same limitation, the age of the mammograms, applies here. The correlation between the automatic area and the cumulus area is similar to that seen in Figure 1. However, the relation between the area measurements is linear, compared to the quadratic relation between Cumulus volume and Cumulus area. The value of $R = .88$ is actually better than is found in tests of inter-observer variability with well trained readers.

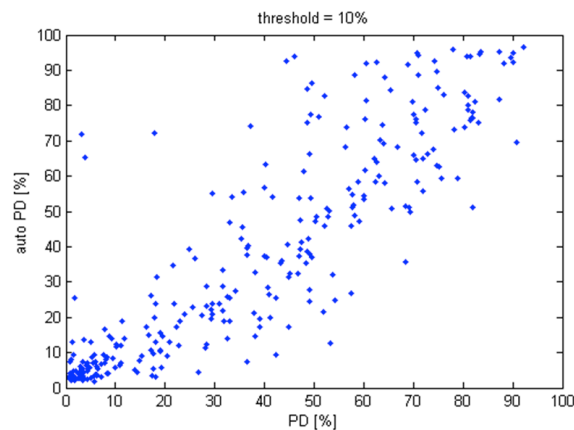


Figure 7: comparison between the PD (percent density using Cumulus area) and the automatic PD. The correlation is $R=0.88$ and the linear least square fit between the two PD measurements is $y=0.97x+2.2\%$,

Task 9: Evaluate precision of 3D Cumulus method (months 7-12) HARVEY

9a. Develop IRB protocol and obtain approval (months 7-8)

Completed. Precision reflects the consistency of a repeated measurement. It does not necessarily reflect the accuracy or validity of the measurement. Precision is important however to the model since changes in breast density will translate to changes in breast cancer risk. Therefore, noise in measurement should be minimal.

Thirty women were recruited under this protocol, which was approved by the UVa IRB and the CDMRP. All women presented for screening mammography. Each patient underwent the standard of practice 4-view mammogram. Following this, a different technologist obtained a second craniocaudal image of the left breast. Density analysis of these 30 paired images was performed to assess the precision, or accuracy of a repeated measure. The paired images were analyzed using Cumulus 2D manually performed by Dr. Harvey and three automated volumetric methods using CumulusV, Volpara, and Quantra. The precision was excellent for all methods. We are currently working on a manuscript.

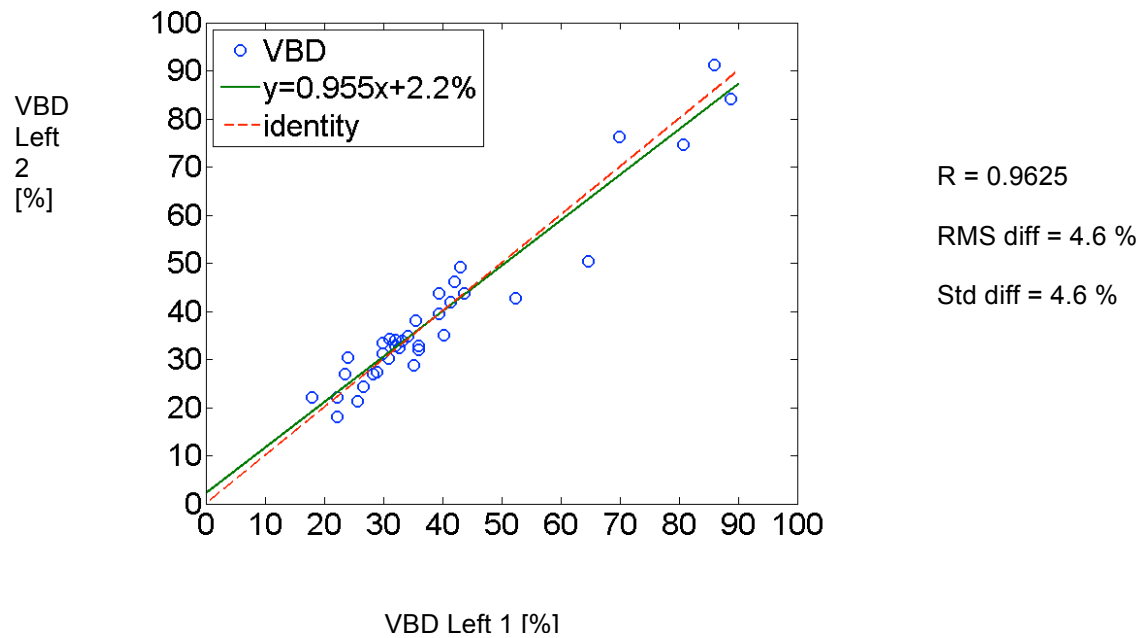


Figure 8. Precision of CumulusV. Excellent precision is present using this method with an R value of 0.96.

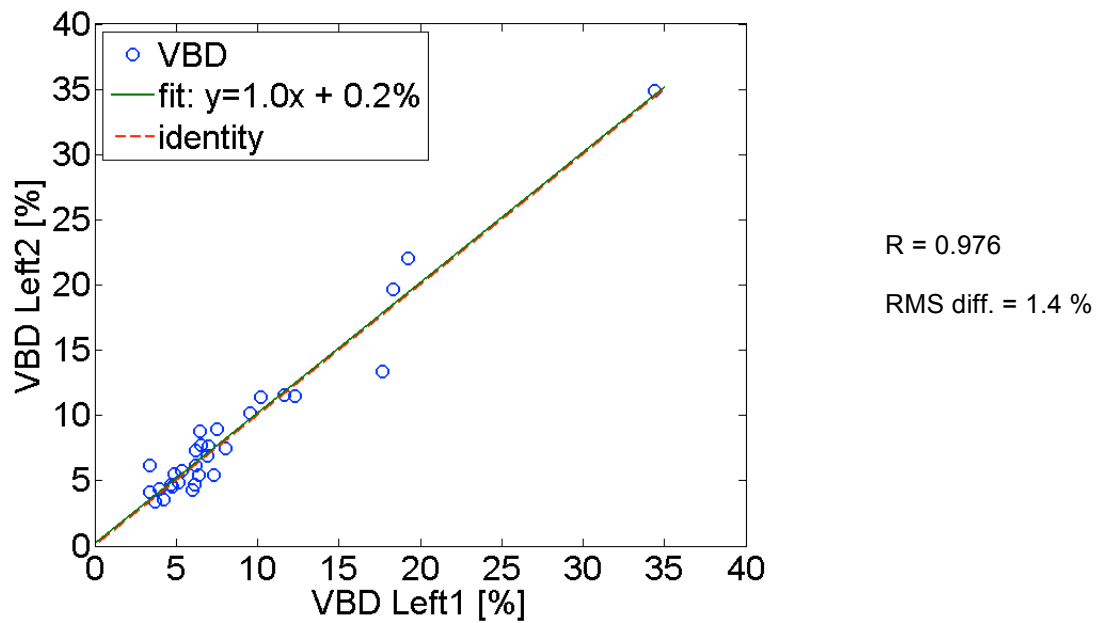


Figure 9. Precision using Volpara density measurement. Precision is similarly very high with an R value of 0.976.

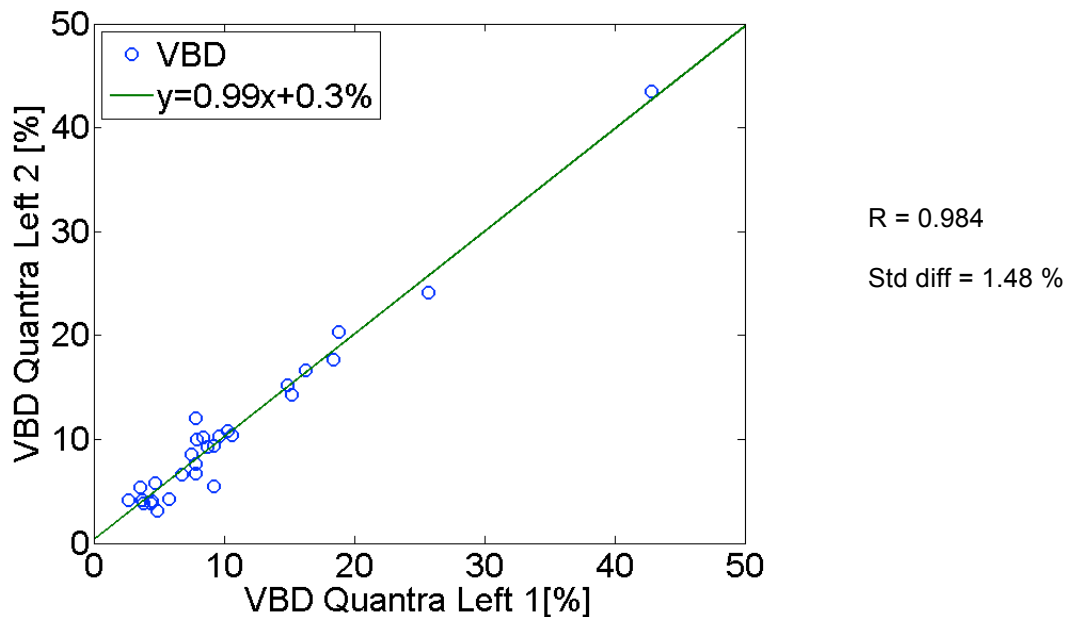


Figure 10. Precision using Quantra density measurement. Also excellent precision with R value of 0.984.

Task 10: Case enrollment (months 7-24) KNAUS

Task 11: Control enrollment (months 8-24) HARVEY

After building the dataset, iPads were programmed for survey data acquisition by the patient. This has been a very efficient, secure system to administer the survey. The data is uploaded to the secure server immediately, and the data is removed from the iPad after completion. A token system has been set up for patient anonymity. Patients can also access the survey from home using their token.

As of October 14, 2013, 622 cases and 2585 control patients have been enrolled for a total of 3207. The characteristics of the case and control population are relatively similar (Table 1).

Table 1. Characteristics of the Study Population

Variable	Cases – Survivors	Controls
Age	62.6 years (SD = 11.5)	61.2 years (SD = 9.7)
Race	83.6% White; 15.2% Black	88.2% White; 11.1% Black
Height	64.2 inches (SD = 2.7)	64.2 inches (SD = 2.9)
Weight	170.1 pounds (SD = 41.1)	160.2 pounds (SD = 36.9)
Educational level	25.7% graduate degree; 18.9% college degree; 25.3% some college; 19.1% high school	29.0% graduate degree; 25.1% college degree; 20.2% some college; 14.9% high school

We have identified 88 deceased women with images that qualify as cases. Chart

abstraction has been performed and data entered for these patients. They are not included in the total above. We have also identified approximately 120 women who qualify as cases who have not been seen at UVa within the last 2 years. Many of our cancer patients receive follow up care in their community. These patients were sent letters to complete the survey online. We are in the process of chart abstraction for the remaining patients to confirm eligibility. With the above 622 recruited cases, the inclusion of the deceased and out of area patients will bring the total to at least 800 cases. We will continue case enrollment through December 2013.

Since we anticipate approximately 3:1 matching, we will need about 2400 control patients. As we already have over 2500 controls, we have concluded recruitment for controls.

We have begun the process of collecting images for study patients. Currently, images for 771 cases and 350 controls have been collected.

As part of the study, we are also requesting the optional donation of a blood sample from patients. The blood sample process was set up after recruitment was underway. We have obtained 1297 blood samples (166 cases, 1091 controls) as of September 21, 2013. These banked samples are stored in a -80 degree Celsius freezer purchased through another grant. These may be helpful if serum hormone levels are needed to further refine the model.

Task 12: Establish accuracy of 3D Cumulus using different machines (months 13-18)
YAFFE

Completed. In order to determine whether the density measurements of mammograms performed on machines from different vendors have significantly different results, and if a “machine type” variable is necessary in the model to control for the variability, a study was performed.

The new dataset used in Task 4 was also used for this task. All women in this dataset had both GE and Hologic mammograms within 15 months. There were 65 patients that qualified for this study.

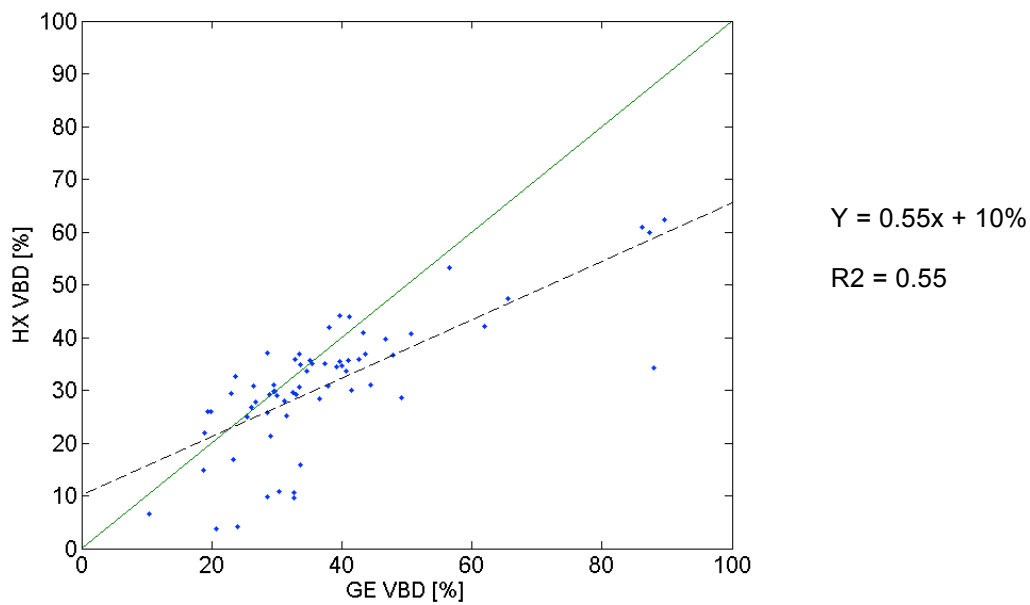


Figure 11. Volumetric breast density (VBD) using CumulusV of mammograms obtained using GE and Hologic machines on the same patient within 15 months. There is moderate correlation. Density measures using images from Hologic machines are uniformly lower than GE.

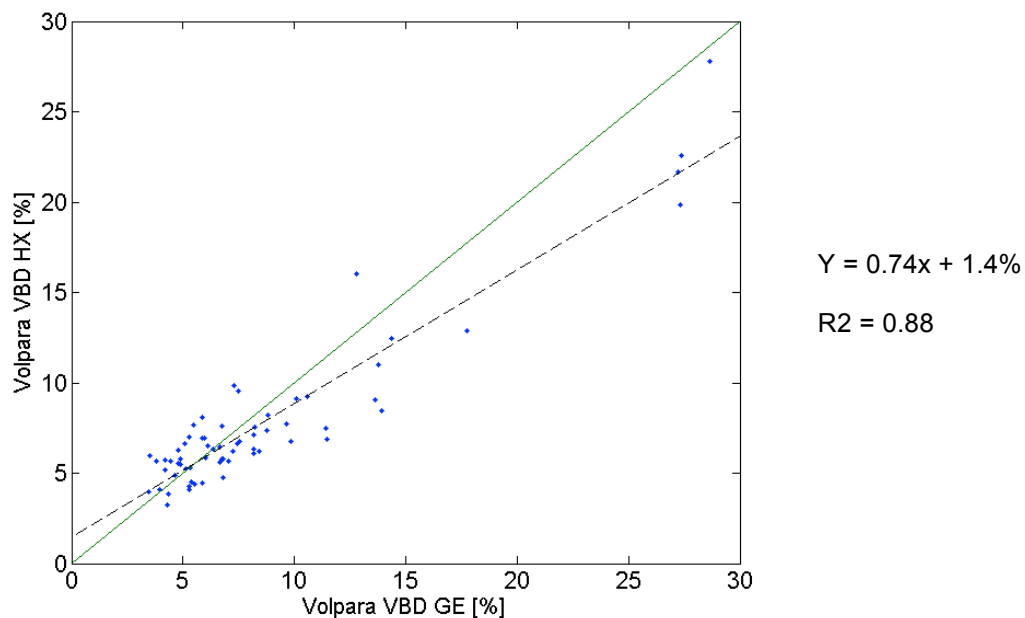


Figure 12. Volumetric breast density (VBD) using Volpara of mammograms obtained using GE and Hologic machines on the same patient within 15 months. There is improved correlation compared with CumulusV. Volpara is less dependent on accurate breast thickness readouts provided by the manufacturers.

Task 13: Finalize database for analysis (months 24-25) KNAUS

Not yet stated as we will continue recruitment of cases through December 2013.

Task 14: Community engagement and publicity campaign (months 1-24) HARVEY

During the first few months of the study, we conducted two focus groups, which were very helpful. The project title is: The UVa Mammography Project: Shaping the Future of Breast Cancer Screening. Our advocates were invaluable in this process.

We created a project website (<http://www.healthsystem.virginia.edu/pub/ct/ct15885>, live date July 2012). We are not using Twitter. However, Vernal Branch, one of our advocates, has posted tweets about the project through the Virginia Breast Cancer Foundation.

The UVa Breast Program Facebook page has increased to 1417 “likes” as of October 15, 2013. Visual aids were developed to inform viewers of the study recruitment status, such as thermometers and pie charts. We produced two 2-minutes videos about the UVA Mammography Project. The last video was posted on September 6, 2013 and has been viewed by over 120 people. There are at least two posts per month; one typically related to the project and one related to a current event.

Representatives from the project were present to provide information at the Charlottesville Four Miler Training Program, packet pick up for the Charlottesville Four Miler Race, Race day for the Charlottesville Four Miler, the Women’s Midlife Forum (May 2013), Relay for Life (June 2013), and Pink Polo (June 2013).

Task 15: Conduct focus groups (months 12-20) HARVEY

The Staff of the Center for Survey Research (CSR) conducted *two initial focus groups* in *January 2012*. The results were very enlightening. The purpose was :

1. To understand what participants know about breast cancer screening and risk
2. To explore participants’ reactions to information about breast density as a risk factor
3. To discuss the Harvey study and motivations for recruiting participants in the study
4. To discuss names for the study

The two focus groups were women without a personal history of breast cancer and women who were breast cancer survivors. The Non-Cancer Group met on January 17, 2012. Eleven participants were recruited who are patients of Dr. Harvey at the Northridge Office or referrals from the UVa Medical staff. The Survivors Group met on January 24, 2012. Nine participants were recruited who are members of a cancer support group coordinated by Diana Cole, at the Emily Couric Clinical Cancer Center, or referrals from Breast Surgery.

Agenda for the Focus Groups:

1. Discussed screening and how participants make decisions about screening
2. Kathy Repich presented Dr. Harvey's slides on risk factors and the existing models for measuring risk
3. Discussed participants' reactions to the presentation and their knowledge of the risk factors
4. Discussed recruitment for the study and what would motivate people to participate in the study
5. Presented ideas for naming the project and gave participants an opportunity to rate them and share others

The non-cancer focus group cited the following as motivating factors for participation in the study: convenience, legitimacy, importance, size of the study, self-education, learn about risk factor models, and altruism ("To help my daughter"). Cancer survivors cited the following as additional motivating factors for participation: to reduce false positives for others, altruism ("I had treatment options because of other trial participants") and "the idea that someday, there may be customized recommendations."

The results of the focus groups lead us to these considerations for messaging on recruitment materials: highlight convenience of participation, address patient privacy, highlight size / scope / potential impact of the study, assess effectiveness of giveaways as recruitment tool – non-cancer group not in favor public display of study participation, and altruism ("Your participation could impact future generations."). We subsequently decided not to give away study logo items (t-shirts, tote bags), but to thank participants with a thank you note highlighting their altruism. The note also includes a \$5 gas card as a token of appreciation.

Two additional focus groups were held in ***January and February 2013***. The purpose was to vet the telephone survey instrument. The additional review was very helpful to address phrasing and to clarify end points.

Task 16. Conduct message testing telephone survey (months 12-20). Harvey

The telephone survey was developed with the UVa Center for Survey Research based on women's responses to the second set of focus groups. Our advocates were very helpful in the development and review of the survey. The survey is attached in Appendix A. As of 15 October 2013, 950 telephone surveys have been conducted.

The goals of the survey are:

- Assess Virginia women's current knowledge about cancer screening recommendations and breast density
- Evaluate willingness of women to change their breast cancer screening practices based on new recommendations
- Identify characteristics of women who are willing and unwilling to change their screening practices

- Inform design of future educational campaigns to promote new tailored recommendations

The survey uses a triple frame scientific random sample that include listed landline phone numbers (random from phone directory), landline RDD-Random Digit Dialing (includes unlisted phone numbers), and cell phone numbers (RDD from cell phone exchanges at Virginia billing centers).

The survey topics include:

- Demographics
- Personal history
- Current breast cancer screening practices
- Risk perception
- Understanding of breast density
- Understanding of current guidelines
- Willingness to change screening practices
- Information sources

A preliminary review of the data was performed and reviewed at our Annual Team Meeting on September 23, 2013. Emerging points of interest include:

- About 24% of women believe that they have a 41-50% chance of being diagnosed with breast cancer during their lifetime.
- Breast density was listed as a risk factor by only 1.7% of respondents
- While most women know that imaging is the best method to detect breast density, about half of women believe that a clinical exam can also give information on the density of the breasts.
- Although over 90% of women know that cancers are more difficult to detect in dense tissue, only about 50% know that breast density increases the risk of cancer.
- Over 50% of women stated that they probably or definitely would not be willing to reduce the frequency of their breast cancer screening.
- Over 75% of women stated that they would probably or definitely be willing to increase their breast cancer screening.
- The most important driver for women to change screening practice was the advice of their doctor. They are also interested in new research evidence.

KEY RESEARCH ACCOMPLISHMENTS:

- Obtained IRB and CDMRP approval for study
- Established a secure database
- Established data elements for survey and set up iPads as survey instruments
- Identified over 2,000 potential cases and over 28,000 controls
- Strong study enrollment. As of October 14, 2012, 3207 women have been recruited and have completed the survey (622 cases and 2585 controls). An

- additional 208 cases have been identified who are deceased or out of area that are being entered into the database. Recruitment of controls is complete. Of all study patients, 1297 have submitted blood samples (optional) (166 cases, 1091 controls).
- Performed outlier correction for area versus CumulusV and Volpara density measurement software programs. The quadratic correlation with manual area density measurement for corrected CumulusV is $R = 0.87$. Second dataset showed R values of 0.84 for CumulusV, 0.88 for Volpara, and 0.85 for Quantra.
 - Developed Automated Cumulus2D software program and compared with manual area density measurements; $R = 0.88$.
 - Precision study completed. The R values for repeated left craniocaudal mammogram images are 0.96 for Cumulus, 0.98 for Volpara, and 0.98 for Quantra.
 - Study completed to evaluate differences in density measures between mammography machine vendors. Density measurements from Hologic machines are uniformly lower than from GE images when using CumulusV ($R = 0.55$). However, the relationship is more linear and consistent when using Volpara ($R = 0.88$).
 - Conducted two focus groups with the help of our advocates and the Center for Survey Research. This formed our messaging for naming the study and recruitment materials.
 - Survey instrument developed and tested. Survey has been administered to 950 of the total 1000 women.
 - Two additional focus groups conducted to vet the telephone survey instrument prior to use.
 - Engaged community through the Charlottesville Women's Four Miler Race and Training Program, Midlife Women's Forum, Relay for Life, and a study website (<http://www.healthsystem.virginia.edu/pub/ct/ct15885>). FaceBook page (UVA Breast Care Program) increased from 44 to 1415 Likes. Two videos posted to page regarding the study in addition to many non-video posts.

REPORTABLE OUTCOMES:

- A process for specimen handling has been established for women donating a blood sample. The samples are divided into 20 serum aliquots and buffy coat for DNA.
- Grant from the Charlottesville Women's Four Miler, \$2400, May 2012, for iPads (survey instrument)
- Grant from the Charlottesville Women's Four Miler, "Breast Cancer Plasma and DNA Bank: use for development of integrative breast cancer risk prediction method." "\$77,733, September 2012. Funds to freeze and store blood samples obtained through this project.
- Two abstracts presented at the International Breast Density Workshop, San Francisco, California, June 9-10, 2013.
 - **Comparison of Breast Density Measurements with a Mammographic Volumetric and Area Algorithm and Magnetic resonance imaging.** O Alonzo-Proulx, JG Mainprize, J Harvey² and MJ Yaffe

- **Estimation of the Precision of Cumulus Area Density and Two Automated Volumetric Breast density Algorithms.** O Alonzo-Proulx, G Mawdlsey, M. Ge, J Harvey and MJ Yaffe
- Survey Instrument for women of screening age evaluating knowledge of screening and breast density, and attitudes toward changes in screening recommendations.

CONCLUSION:

We have completed the vast majority of tasks designated for our first two years. During this second year, we developed an organized approach to case recruitment that was very successful. Community engagement through attendance at events, a website, and Facebook page was very helpful in this successful. Recruitment of controls has been completed. We will end recruitment with approximately 800 cases: 2500 controls, which is well above our necessary minimum of 600 cases. We have evaluated breast density measurements in several ways this year: a second test set showed very good correlation between the gold standard Cumulus 2D and the volumetric methods (CumulusV, Volpara), precision was shown to be very high for all volumetric density programs, and differences between the major mammography machine vendors (GE and Hologic) were shown to be negligible for Volpara but with differing readings for CumulusV. A survey instrument was developed, vetted in two focus groups, and has been administered to 950 of the total 1000 women target.

REFERENCES:

None

APPENDICES:

Survey instrument

**APPENDIX I: UVA MAMMOGRAPHY PROJECT: SURVEY ON TAILORED
BREAST CANCER SCREENING**

[DRAFT]

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NOTE TO PROGRAMMER: SKIP INSTRUCTIONS ARE INCLUDED WITHIN THE
RESPONSE LABELS FOR THE INTRODUCTION SECTION. THESE SHOULD
NOT BE DISPLAYED.

A. INTRODUCTION

INTRO SECTION FOR LISTED AND RDD SAMPLES

{Q: INTRO}

Hello. My name is _____ and I am calling from the Center for Survey Research at the University of Virginia. We are conducting a survey of Virginia women between the ages of 35 and 70 for a group of medical researchers at the University of Virginia. I am NOT asking for donations or selling anything. Your household was selected at random to be part of our sample.

- 1 NO ANSWER/TEMP UNAVAIL
- 2 BUSY /NETWORK BUSY
- 3 ANS MACH/VOICEMAIL/SYSTEM MSG
- 4 BAD NUMBER / WRONG PHONE TYPE
- 5 IMMEDIATE HANGUP
- 6 IMMEDIATE REFUSAL
- 7 CALLBACK/CALL LANDLINE
- 8 IMMEDIATELY INDICATES INELIGIBLE
- 9 GO ON (F5 FOR CASE INFO) [GO ON TO ADULTRES]

[IF FINISHING INCOMPLETE SURVEY]

Hello. My name is _____ and I am calling from the Center for Survey Research at the University of Virginia. We are conducting a survey of Virginia women between the ages of 35 and 70 for a group of medical researchers at the University of Virginia. Your household was selected at random to be part of our sample, and we had started a survey with someone in your home but were unable to complete it. Would this be a good time to finish up the questions?

INTERVIEWER: IF NECESSARY - We're calling from the University of Virginia on behalf of a group of medical researchers at the University. We're not selling anything.

{Q: ADULTRES}

First, I need to confirm that you are at least 18 years old, and that you live at the residence I am calling. [IF NECESSARY SAY: Your answers are confidential, and we don't use anybody's name.]

- 1 R IS RESIDENT ADULT, PROCEED [SKIP TO VARES]
- 2 R IS NOT RESIDENT OR ADULT, WE NEED TO GET ONE [GO ON TO ADCOME]
- 3 REFUSED

{Q: ADCOME}

[ASK IF ADULTRES = 2]

Can you ask someone 18 or older who lives in your house to come to the phone?

- 1 YES, ASKING RESIDENT ADULT TO COME TO THE PHONE [SKIP TO REINTRO]
- 2 NO, CAN'T ASK RESIDENT ADULT TO COME TO THE PHONE [GO ON TO ADCALLBK]

- 3 REFUSES TO ASK RESIDENT ADULT TO COME TO PHONE
[TERMINATE]

{Q: ADCALLBK}

[ASK IF ADCOME = 2]

Would it be possible to reach this person at another time?

- 1 YES, SCHEDULE CALLBACK
- 2 NO (OR NOT SURE), ADULT NOT AVAILABLE DURING STUDY PERIOD [TERMINATE]
- 3 REFUSED [TERMINATE]

{Q: REINTRO}

[ASK IF ADCOME = 1]

Hello. My name is _____ and I am calling from the Center for Survey Research at the University of Virginia. We are conducting a survey of Virginia women between the ages of 35 and 70 for a group of medical researchers at the University of Virginia. I am NOT asking for donations or selling anything. Would you be willing to help us out by answering a few questions?

- 1 R1 READY, PROCEED [SKIP TO VARES]
- 2 R1 CALLBACK [GET NAME OF R1 FOR CALLBACK MESSAGE LINE]
- 3 R1 REFUSED [TERMINATE]

{Q: VARES}

I need to confirm that you are a resident of Virginia.

- 1 YES [GO ON TO GENDER]
- 2 NO [TERMINATE]
- 3 DON'T KNOW/REFUSED [TERMINATE]

{Q: GENDER}

[ENTER RESPONDENT'S GENDER: ASK ONLY IF NECESSARY: SAY: "The survey requires that you tell me your gender."]

- 1 MALE [SKIP TO HOWMANY2]
- 2 FEMALE [GO ON TO ELIGAGE]
- 3 REFUSED [SKIP TO HOWMANY2]

{Q: ELIGAGE}

[ASK IF GENDER = 2]

And are you between the ages of 35 and 70 years old? [AGES 35 AND 70 ARE ELIGIBLE]

- 1 YES [GO ON TO ELIGBC]
- 2 NO [SKIP TO HOWMANY2]
- 3 R1 SAYS THERE ARE NO WOMEN IN THE HOUSEHOLD IN THAT AGE RANGE [TERMINATE]
- 4 DK/REF [SKIP TO HOWMANY2]

{Q: ELIGBC}

[ASK IF ELIGAGE = 1]

And have you ever been diagnosed with breast cancer?

- 1 YES [SKIP TO HOWMANY2]
- 2 NO [GO ON TO HOWMANY1]
- 3 DK/REF [SKIP TO HOWMANY2]

{Q: HOWMANY1}

[ASK IF GENDER = 2 AND ELIGAGE = 1]

To ensure a valid survey, I need to randomly select a woman in your household to complete the interview.

[IF NECESSARY: If we always interview the person who answers the phone the survey will not accurately reflect the opinions of the whole population.] So, could you please tell me how many women between the ages of 35 and 70 there are in your household, including yourself, who have never been diagnosed with breast cancer? [AGES 35 AND 70 ARE ELIGIBLE]

_____ Women (TYPE "99" FOR REFUSED)

- If there is only 1 eligible woman in the household, then skip to R1GO.
- If there are 2 eligible women in the household, then 50% skip to R1GO and the other 50% go on to R2COME.
- If there are 3 eligible women in the household, then 33% skip to R1GO and the other 67% go on to YOUNGST1.
- If there are 4 eligible women in the household, then 25% skip to R1GO and the other 75% go on to YOUNGST1.
- And so on.
- If REFUSED, then skip to YOUNGST3.

{Q: HOWMANY2}

[ASK IF GENDER = 1 OR 3, OR ELIGAGE = 2 OR 4]

To ensure a valid survey, I need to randomly select a woman in your household to complete the interview. So, could you please tell me how many women between the ages of 35 and 70 there are in your household who have never been diagnosed with breast cancer? [AGES 35 AND 70 ARE ELIGIBLE]

_____ Women (TYPE "99" FOR REFUSED)

- If there are no eligible women in the household, TERMINATE.
- If there is only 1 eligible woman in the household, then skip to R2COME.
- If there are 2 or more eligible women in the household, then go on to YOUNGST2.
- If REFUSED, then skip to YOUNGST3.

{Q: YOUNGST1}

[ASK IF GENDER = 2 AND ELIGAGE = 1]

The computer has randomly determined that one of the women other than yourself should be selected for the rest of the interview. According to our selection procedure, this time I need to select the youngest woman in your household, other than yourself, who is at least 35 years old and has never been diagnosed with breast cancer. Do you know who that is?

- 1 R1 SAYS YES, KNOWS YOUNGEST OTHER WOMAN [SKIP TO R2COME]
- 2 R1 SAYS DOESN'T KNOW YOUNGEST OTHER WOMAN [GO ON TO R2KISH]
- 3 REFUSES TO SAY WHO IS YOUNGEST OTHER WOMAN/ R1 REFUSES TO CONTINUE [TERMINATE]

{Q: YOUNGST2}

[ASK IF GENDER = 1 OR 3, OR ELIGAGE = 2 OR 4]

According to our selection procedure, this time I need to select the youngest woman in your household who is at least 35 years old and has never been diagnosed with breast cancer. Do you know who that is?

- 1 R1 SAYS YES, KNOWS YOUNGEST OTHER WOMAN [SKIP TO R2COME]
- 2 R1 SAYS DOESN'T KNOW YOUNGEST OTHER WOMAN [GO ON TO R2KISH]
- 3 REFUSES TO SAY WHO IS YOUNGEST OTHER WOMAN/ R1 REFUSES TO CONTINUE [TERMINATE]

{Q: YOUNGST3}

[ASK IF HOWMANY1 = 99 OR HOWMANY2 = 99]

Then our next selection criterion is to select the youngest woman in your household who is at least 35 years old and has never been diagnosed with breast cancer. Do you know who that is?

- 1 R1 IS YOUNGEST WOMEN [SKIP TO R1GO]
- 2 R1 SAYS YES, KNOWS YOUNGEST WOMAN [SKIP TO R2COME]
- 3 R1 SAYS DOESN'T KNOW YOUNGEST WOMAN [GO ON TO R2KISH]
- 4 REFUSES TO SAY WHO IS YOUNGEST WOMAN/ R1 REFUSES TO CONTINUE [TERMINATE]

{Q: R2KISH}

[ASK IF YOUNGST1 = 2 OR YOUNGST2 = 2 OR YOUNGST3 = 3]

If you do not know the youngest woman in your household, could you tell me the first name of the [other] women ages 35 to 70 in the household who have never been diagnosed with breast cancer? [AGES 35 AND 70 ARE ELIGIBLE]

- 1 R1 SAYS YES [GO ON TO R2NAMES]
- 2 R1 DOESN'T KNOW [TERMINATE]
- 3 R1 REFUSES TO CONTINUE [TERMINATE]

{Q: R2NAMES}

[ASK IF R2KISH = 1]

Now, the computer will randomly select a name from the list of names as you tell them to me. Please say the names now.

INTERVIEWER: HIT "1" EACH TIME A NAME IS SPOKEN OUT
[SKIP TO R2COME WHEN R SELECTED]

{Q: R1GO}

Okay, let's move on to the rest of the survey, which should take about 20 minutes. The questions are about your experience with mammography screening and breast cancer. Your answers are very important because what we will learn from this survey will be used in designing cancer screening and education programs here in Virginia and in other states. All of your answers will be confidential, and you can decline to answer any question at any time.

[IF NECESSARY: This survey is being conducted by the Center for Survey Research at the University of Virginia. If you have any questions as we go along, please feel free to ask.]

- 1 R1 READY [GO TO CELLLAND]
- 2 R1 CALLBACK [GET NAME OF R1 FOR CALLBACK MESSAGE LINE]
- 3 R1 REFUSED [TERMINATE]

{Q: R2COME}

[ASK IF YOUNGST1 = 1 OR YOUNGST2 = 1 OR YOUNGST3 = 1 OR R2KISH = 1]

Can you ask that person to come to the phone?

- 1 YES, R1 ASKING R2 TO COME TO PHONE [SKIP TO R2INTRO]
- 2 NO, CAN'T ASK R2 TO COME TO PHONE [GO ON TO R2CALLBK]
- 3 R1 REFUSES TO ASK PERSON TO COME TO PHONE [TERMINATE]

{Q: R2CALLBK}

[ASK IF YOUNGST1 = 2 OR YOUNGST2 = 2 OR YOUNGST3 = 2]

Would it be possible to reach this person at another time?

- 1 YES, SCHEDULE CALLBACK
- 2 NO (OR NOT SURE), R2 IS NOT AVAILABLE DURING STUDY PERIOD [TERMINATE]
- 3 REFUSED [TERMINATE]

{Q: R2INTRO}

[ASK IF R2COME = 1]

Hello, my name is _____ and I am calling from the Center for Survey Research at the University of Virginia. We are conducting a survey of Virginia women between the ages of 35 and 70 for a group of medical researchers at the University of Virginia. I am NOT asking for donations or selling anything. Do you think you could help me out by answering a few questions about your experience with mammography screening and breast cancer?

Your answers are very important because what we will learn from this survey will be used in designing cancer screening and education programs here in Virginia and in other states.

- 1 R2 READY, PROCEED [GO ON TO R2GO]
- 2 R2 CALLBACK [GET NAME OF R2 FOR CALLBACK MESSAGE LINE]
- 3 R2 CAME TO PHONE, BUT REFUSED [CANNOT SWITCH BACK TO R1]
- 4 R2 WOULD NOT COME TO PHONE [CANNOT SWITCH BACK TO R1]

{Q: R2GO}

[ASK IF R2INTRO = 1]

Okay, let's move on to the rest of the survey, all of your answers are confidential, and you can decline to answer any question at any time. [IF NECESSARY: This survey is being conducted by the Center for Survey Research at the University of Virginia. If you have any questions as we go along, please feel free to ask.]

- 1 R2 READY, PROCEED [SKIP TO CELLLAND]
- 2 R2 CALLBACK [GET NAME OF R2 FOR CALLBACK MESSAGE LINE]
- 3 R2 REFUSES [TERMINATE]

INTRO SECTION FOR CELL PHONE SAMPLE

{Q: INTRO}*

Hello. My name is _____ and I am calling from the Center for Survey Research at the University of Virginia. We are conducting a survey of Virginia women between the ages of 35 and 70 for a group of medical researchers at the University of Virginia. I am NOT asking for donations or selling anything. Your cell phone number was randomly selected to be part of our sample. If you are currently doing any activity that requires your full attention, I need to call you back at a later time.

- 1 NO ANSWER/TEMP UNAVAIL
- 2 BUSY /NETWORK BUSY
- 3 ANS MACH/VOICEMAIL/SYSTEM MSG
- 4 BAD NUMBER / WRONG PHONE TYPE
- 5 IMMEDIATE HANGUP
- 6 IMMEDIATE REFUSAL
- 7 CALLBACK/CALL LANDLINE
- 8 GO ON (F5 FOR CASE INFO)

[IF FINISHING INCOMPLETE SURVEY]

Hello. My name is _____ and I am calling from the Center for Survey Research at the University of Virginia. We are conducting a survey of Virginia women between the ages of 35 and 70 for a group of medical researchers at the University of Virginia. You were selected at random to be part of our sample, and we had started a survey with you but were unable to complete it. Would this be a good time to finish up the questions?

{Q: GENDER}*

[ENTER RESPONDENT'S GENDER: ASK ONLY IF NECESSARY: SAY: "The survey requires that you tell me your gender."]

- 1 MALE [TERMINATE]
- 2 FEMALE
- 3 REFUSED [TERMINATE]

{Q: VARESCEL}*

I need to confirm that you are a Virginia resident.

- 1 YES
- 2 NO [TERMINATE]
- 3 DON'T KNOW/REFUSED [TERMINATE]

{Q: ELIGAGE}*

I also need to ask if you are between the ages of 35 and 70 years old?

- 1 YES
- 2 NO [TERMINATE]
- 3 DON'T KNOW/REFUSED [TERMINATE]

{Q: ELIGBC}

[ASK IF ELIGAGE = 1]

Finally, I need to know if you have ever been diagnosed with breast cancer?

- 1 YES [TERMINATE]
- 2 NO [GO TO R1GO]
- 3 DK/REF [TERMINATE]

INTRO SECTION FOR ALL RESPONDENTS

{Q: CELLLAND}

To begin we have a few questions about how we reached you.

Are you speaking to me on a cellular telephone or on a regular, landline phone located in your home? [IF NECESSARY SAY: By cellular telephone, we mean a telephone that is mobile and usable outside of your neighborhood.]

- 1 CELL PHONE [GO TO CELLSAFE]
- 2 REGULAR OR LANDLINE PHONE [GO TO OWNCELL]
- 3 VOICE OVER IP [VOLUNTEERED] [GO TO OWNCELL]
- 4 DON'T KNOW/REFUSED

{Q: CELLSAFE}

[ASK IF CELLLAND = 1]

If you are doing something that requires your full attention, then I can call you back at a later time at this number or on a landline phone.

- 1 GO ON [GO TO CELLUSE]
- 2 CALL BACK

{Q: OWNCELL}

[ASK IF CELLLAND = 2 OR CELLLAND = 3]

Do you also have a cell phone for your personal use?

- 1 YES [GO TO CELLUSE]
- 2 NO
- 3 DON'T KNOW/REFUSED

{Q: CELLUSE}

[ASK IF CELLLAND = 1 OR OWNCELL = 1]

Is this cell phone used for . . . ? [IF R SAYS: "I have one phone for business and one for personal," ASK "Which is the one I reached?"

- 1 Personal use only
- 2 Business use only [TERMINATE]
- 3 Personal and business use
- 4 CALLBACK
- 5 DON'T KNOW/NOT SURE
- 6 REFUSED

{Q: CELLUSE}

[ASK IF CELLLAND = 1]

Do you also have a regular telephone at home? [IF NECESSARY SAY: By regular telephone, we mean a land line telephone.]

- 1 YES
- 2 NO
- 3 YES, VOICE OVER INTERNET PROTOCOL SERVICE (VOIP)
[VOLUNTEERED]
- 4 DON'T KNOW/NOT SURE
- 5 REFUSED

B. PERSONAL HISTORY

The research group sponsoring this survey is currently conducting a study about tailored or personalized recommendations for breast cancer screening. Using scientific methods, they are hoping to develop a set of recommendations based on a woman's individual risk factors that will improve early detection of breast cancer while reducing the number of unnecessary tests and procedures.

The first questions I have are about your cancer history and experience with breast cancer screening. Please remember that all of your answers are confidential, and you don't have to answer any question you don't want to.

{Q: DIAGFAM}

Have any of your blood relatives ever been diagnosed with breast cancer?

[IF NECESSARY, SAY: This does not include people related to you through marriage or adoption.]

- 1 YES
- 2 NO
- 3 DK/REF

{Q: NUMFAM}

[ASK IF DIAGFAM=1]

How many have ever had this diagnosis?
_____ (20 or more=20, DK/REF=99)

{Q: CANCER}

Have you ever been diagnosed with cancer of any kind?

- 1 YES
- 2 NO
- 3 DK/REF

C. CURRENT SCREENING PRACTICES

{Q: CHECK}

Women we talk to have different ways of checking themselves for breast cancer, or being checked or screened by a health care professional. Have you done anything in the last five years to check for breast cancer?

- 1 YES
- 2 NO
- 3 DK/REF

{Q: HOWCHECK}

[ASK IF CHECK=1]

What have you been doing for breast cancer screening or detection? (SELECT ALL THAT APPLY)

- 1 SELF-EXAMINATION
- 2 WATCHING FOR BREAST CANCER SYMPTOMS
- 3 CLINICAL BREAST EXAMS PERFORMED BY A MEDICAL PROFESSIONAL
- 4 MAMMOGRAM
- 5 OTHER BREAST IMAGING TEST (E.G., MRI, ULTRASOUND)
- 6 THERMOGRAPHY
- 7 NOTHING
- 8 DK/REF

PROBE: ANYTHING ELSE?

IF NECESSARY: JUST THE LAST 5 YEARS

{Q: MAMMO}

[SKIP IF HOWCHECK = 4]

Have you ever had a mammogram?

[IF NECESSARY, SAY: A mammogram is a test used to find breast cancer. An X-ray is taken of each breast separately by a machine that flattens or squeezes each breast.]

- 1 YES
- 2 NO
- 3 DK/REF

{Q: MAMMO2}

[SKIP IF HOWCHECK = 5]

Have you ever had any other breast imaging procedure designed to detect breast cancer (for example, an MRI or ultrasound?)

- 1 YES
- 2 NO
- 3 DK/REF

{Q: ROUTINE}

[ASK IF MAMMO=1]

How often do you currently go for a routine mammogram?

[IF NECESSARY, SAY: A routine mammogram is done for check-up purposes only. This type of mammogram is done for a woman who has not had symptoms or breast problems at the time of the mammogram.]

- 1 Every 6 months
- 2 Every year
- 3 Every 2 years
- 4 Every 3-5 years
- 5 Less often than every 5 years
- 6 Never
- 7 NO REGULAR PATTERN, JUST 1 OR 2 TIMES
- 8 DK/REF

{Q: LSTMAMMO}

[ASK IF MAMMO=1]

When did you have your most recent mammogram? Was it:

- 1 Less than 1 year ago
- 2 1-2 years ago
- 3 3-4 years ago
- 4 5 or more years ago
- 5 DK/REF

{Q: ABNORMAL}

[ASK IF MAMMO=1]

Have you ever had a mammogram where the results were abnormal, or you were called back?

- 1 YES
- 2 NO
- 3 DK/REF

{Q: ADDTEST}

[ASK IF ABNORMAL=1]

Because of these results, did you have any of the following tests? (SELECT ALL THAT APPLY)

- 1 Another mammogram
- 2 Ultrasound of the breast
- 3 MRI of the breast
- 4 OTHER [specify:]

- 5 NONE
- 6 DK/REF

{Q: ADDSURG}

[ASK IF ABNORMAL=1]

Because of these results, did you have any of the following procedures? (SELECT ALL THAT APPLY)

- 1 Needle biopsy (NEEDLE INSERTED INTO THE BREAST AND CELLS OR TISSUE REMOVED)
- 2 Tumor or lump was removed (LUMPECTOMY)
- 3 Breast removed (MASTECTOMY)
- 4 OTHER [specify:]
- 5 NONE
- 6 DK/REF

{Q: FALSEPOS}

[ASK IF ABNORMAL=1]

Did you ever have a breast cancer scare because of the testing, or a false positive? [IF NECESSARY, SAY: A false positive is when a mammogram has non-normal results but follow-up tests or surgeries reveal that you do not have breast cancer.

- 1 YES
- 2 NO
- 3 DK/REF

{Q: NOMAMMO}

[ASK IF MAMMO=2 OR LSTMAMMO = 3 OR 4]

There are many reasons why a woman might not have had a mammogram. What are the reasons you have not had a mammogram in the last 2 years? (SELECT ALL THAT APPLY)

- 1 NO REASON/NEVER THOUGHT OF IT
- 2 DIDN'T NEED IT/DIDN'T KNOW I NEEDED THIS TYPE OF TEST
- 3 DOCTOR DIDN'T ORDER IT/DIDN'T SAY I NEEDED IT
- 4 HAVEN'T HAD ANY PROBLEMS
- 5 PUT IT OFF/DIDN'T GET AROUND TO IT
- 6 COST /TOO EXPENSIVE/NO INSURANCE
- 7 TOO PAINFUL, UNCOMFORTABLE
- 8 EMBARRASSING, UNPLEASANT
- 9 INCREASED EXPOSURE TO RADIATION
- 10 FEAR OF THE RESULTS
- 11 INCONVENIENT/CAN'T GET OFF WORK
- 12 I'M TOO YOUNG
- 13 I'M TOO OLD
- 14 DON'T HAVE A DOCTOR
- 15 OTHER REASON [SPECIFY]
- 16 DK/REF

{Q: PLNMAMMO}

Do you plan to have a mammogram in the future?

- 1 YES
- 2 NO
- 3 DK/REF
- 4 UNSURE

{Q: FUTMAMMO}

[ASK IF PLNMAMMO=1]

When do you plan to have a mammogram in the future? (SELECT ALL THAT APPLY)

- 1 WITHIN THE NEXT 6 MONTHS
- 2 IN 6 MONTHS TO 1 YEAR
- 3 IN 1-2 YEARS
- 4 IN 3-4 YEARS
- 5 IN 5 OR MORE YEARS
- 6 WHEN I TURN 40
- 7 WHEN I TURN 50
- 8 WHEN MY DOCTOR RECOMMENDS
- 9 WHEN I HAVE A SYMPTOM
- 10 NOT PLANNING TO HAVE ONE
- 11 DK/REF

D. RISK PERCEPTION

{Q: OWNRISK}

We are interested in what you think about your own risk for breast cancer. How would you estimate your own chance of getting breast cancer in the future? Would you say it is:

- 1 More than the average woman
- 2 Same as the average woman
- 3 Less than the average woman
- 4 DK/REF

{Q: OWNRISK2}

[ASK IF OWNRISK = 1]

Would you say that your risk is much more or a little more than the average woman?

- 1 MUCH MORE THAN THE AVERAGE WOMAN
- 2 A LITTLE MORE THAN THE AVERAGE WOMAN
- 3 DK/REF

{Q: OWNRISK3}

[ASK IF OWNRISK = 3]

Would you say that your risk is much less or a little less than the average woman?

- 1 MUCH LESS THAN THE AVERAGE WOMAN
- 2 A LITTLE LESS THAN THE AVERAGE WOMAN
- 3 DK/REF

{Q: PCTRISK}

As a percentage (0 to 100 percent), what do you think your chance is of developing breast cancer in your lifetime? _____ (Range 0-100, DK=998, REF=999)

{Q: FAMLRISK}

How familiar would you say you are with the risk factors for breast cancer?

- 1 Very familiar
- 2 Somewhat familiar
- 3 Slightly familiar
- 4 Not familiar
- 5 DK/REF

{Q: RECMRISK}

[ASK IF FAMLRISK <= 3]

Scientists and doctors have looked at a lot of possible risk factors for breast cancer. Based on what you've heard, what are some of the factors that can affect a woman's risk of developing breast cancer? (SELECT ALL THAT APPLY)

- 1 AGE
- 2 AGE AT FIRST OR LAST MENSTRUATION
- 3 ALCOHOL USE
- 4 ANTIPERSPIRANT USE
- 5 BIRTH CONTROL PILL USE
- 6 BREAST BIOPSY WITH OR WITHOUT ATYPIA/HIGH RISK LESION
- 7 BREAST SIZE
- 8 BREAST TISSUE DENSITY
- 9 BREASTFEEDING
- 10 CHEST RADIATION EXPOSURE
- 11 DIET/WHAT YOU EAT
- 12 FAMILY HISTORY OF BREAST CANCER
- 13 FREQUENCY OF WEARING A BRA
- 14 GENDER (FEMALE)
- 15 HAVING NO CHILDREN OR HAVING THEM LATER
- 16 HORMONE THERAPY USE
- 17 INHERITED GENETIC MUTATIONS (BRCA 1, BRCA 2, ETC)
- 18 PERSONAL HISTORY OF ABORTION OR MISCARRIAGE
- 19 PERSONAL HISTORY OF BREAST CANCER
- 20 PERSONAL HISTORY OF OTHER BREAST DISEASE
- 21 PHYSICAL ACTIVITY
- 22 RACE AND ETHNICITY
- 23 SMOKING/TOBACCO USE
- 24 VITAMIN D LEVELS
- 25 WEIGHT/OBESITY
- 26 OTHER [SPECIFY]
- 27 DK
- 28 REF

PROBE: ANYTHING ELSE?

{Q: SRCRISK}

From which of the following sources have you obtained information about your level of risk for breast cancer? (SELECT ALL THAT APPLY)

- 1 Health care professional (doctor, nurse, etc.)
- 2 Pamphlets provided in doctor's office or hospital
- 3 Family and/or friends
- 4 Pastor or spiritual advisor
- 5 Patient support group
- 6 Television or Radio
- 7 Newspapers or magazines
- 8 Books
- 9 Medical journals
- 10 Medical sponsor website (NIH, WebMD etc)
- 11 Other Internet website
- 12 Social media, (Facebook, Twitter etc)
- 13 Other [SPECIFY]
- 14 DON'T KNOW
- 15 REFUSED

E. UNDERSTANDING OF BREAST DENSITY

The next few questions are about breast density. Breast density is a measure used to describe the proportion of the different tissues that make up a woman's breasts.

{Q: FAMDENSE}

How familiar are you with the concept of breast density?

- 1 Very familiar
- 2 Somewhat familiar
- 3 Slightly familiar
- 4 Not familiar
- 5 DK
- 6 REF

{Q: FINDENSE}

[ASK IF FAMDENSE = 1,2 OR 3]

Which of the following methods can be used to identify breast density? (SELECT ALL THAT APPLY)

- 1 The size and shape of the breasts
- 2 Breast self-examination
- 3 Breast exam by a medical professional
- 4 Breast imaging such as a mammogram, CT scan, or MRI
- 5 DK
- 6 REF

{Q: DOCDENSE}

Has your doctor ever informed you about the density of your breasts?

- 1 YES
- 2 NO
- 3 DK
- 4 REF

{Q: HRDDENSE}

Have you ever heard anything about the relationship between breast density and breast cancer risk?

- 1 YES
- 2 NO
- 3 DK
- 4 REF

{Q: HRDWHAT1}

[ASK IF HRDDENSE=1]

Would you say that the risk of breast cancer is higher for...

- 1 A woman with high breast density,
- 2 A woman with low breast density, or is it
- 3 Equal for both, or
- 4 Don't know.

{Q: HRDWHAT2}

[ASK IF HRDDENSE=1]

Let's say a woman has a mammogram and the radiologist is reading the results to see if she has any tumors. Will it be harder to detect tumors for...

- 1 A woman with high breast density,
- 2 A woman with low breast density, or is it
- 3 Equal for both, or
- 4 Don't know.

{Q: HRDWHERE}

[ASK IF HRDDENSE=1]

From which of the following sources did you hear about the link between breast density and breast cancer risk? (SELECT ALL THAT APPLY)

- 1 Health care professional (doctor, nurse, etc.)
- 2 Pamphlets provided in doctor's office or hospital
- 3 Family and/or friends
- 4 Pastor or spiritual advisor
- 5 Patient support group
- 6 Television or Radio
- 7 Newspapers or magazines
- 8 Books

- 9 Medical journals
- 10 Medical sponsor website (NIH, WebMD etc)
- 11 Other Internet website
- 12 Social media, (Facebook, Twitter etc)
- 13 Other [SPECIFY]
- 14 DON'T KNOW
- 15 REFUSED

{Q: DEFENSE}

[SKIP IF FAMDENSE=1 & HRDWHAT = 1 & HRDWHAT = 1]

Here is a little more information about breast density. Breast density is defined as the amount of breast and connective tissue seen on a mammogram relative to the amount of fatty tissue. Women with high breast density have more white, or dense, tissue seen on their mammogram, while women with low breast density have more gray, or fatty, tissue on their mammogram. There is substantial medical research showing that high breast density increases a woman's risk for breast cancer and makes it harder to detect tumors with a mammogram.

F. UNDERSTANDING OF CURRENT GUIDELINES

Now, I have some more questions for you. The medical community and cancer organizations have issued general recommendations about when and how often women should start receiving regular breast cancer screening. We're interested in how well known some of these recommendations are.

{Q: FAMLRECM}

How familiar would you say you are with the recommendations for breast cancer screening?

- 1 Very familiar
- 2 Somewhat familiar
- 3 Slightly familiar
- 4 Not familiar
- 5 DON'T KNOW/REFUSED

{Q: RECMAGE}

At what age are women usually recommended to start having regular mammograms, assuming that they do not have any unusual risk factors and have not been diagnosed with breast cancer?

- 1 20 years
- 2 30 years
- 3 40 years
- 4 50 years
- 5 60 years
- 6 OTHER [SPECIFY]
- 7 DON'T KNOW

8 REFUSED

{Q: RECMFREQ}

How often is it recommended that women over age 50 have regular mammograms?

READ AS NECESSARY

- 1 EVERY THREE MONTHS
- 2 EVERY SIX MONTHS
- 3 ONCE A YEAR
- 4 EVERY OTHER YEAR
- 5 EVERY 3-4 YEARS
- 6 EVERY 5 YEARS OR LESS OFTEN
- 7 DEPENDS ON THE WOMAN'S AGE
- 8 OTHER [SPECIFY]
- 9 DON'T KNOW
- 10 REFUSED

G. TAILORED RECOMMENDATIONS FOR SCREENING

As I mentioned, we are considering tailored or personalized recommendations for breast cancer screening. These new recommendations could advise some women to receive breast cancer screenings more often or to use different testing procedures. Other women could be advised to have screenings less often, depending on their individual characteristics. The recommendations would be based on risk factors for breast cancer such as family history, breast density, and lifestyle.

Imagine that the research is finished and there are a new set of recommendations available for breast cancer screening practices.

[IF MAMMO = 2 (NO) OR ROUTINE = 5 OR 6 (LESS OFTEN THAN EVERY 5 YEARS OR NEVER) SKIP TO HIRISK1A]

{Q: LOWRISK1}

Suppose that, based on these new tailored recommendations, your health care provider advised you to have a mammogram less often than you currently do. Would you be willing to reduce your frequency of breast cancer screening?

IF NO HEALTH CARE PROVIDER, SAY: Suppose you were so advised by a health care practitioner.

- 1 Definitely
- 2 Probably
- 3 Probably not
- 4 Definitely not
- 5 DON'T KNOW/REFUSED

{Q: LOWRISK2}

[ASK IF LOWRISK1 = 3 OR 4]

Why might you be unwilling to reduce your frequency of breast cancer screening?
(SELECT ALL THAT APPLY)

- 1 RISK OF CANCER TOO GREAT
- 2 NOT RECOMMENDED BY A DOCTOR
- 3 MISTRUST OF GUIDELINES/RECOMMENDATIONS
- 4 KNOW TOO MANY WOMEN WITH CANCER
- 5 HABIT
- 6 ALREADY HAVE VERY INFREQUENT SCREENINGS
- 7 OWN PEACE OF MIND
- 8 OTHER [SPECIFY]
- 9 DON'T KNOW/REFUSED

{Q: LOWRISK3}

[ASK IF LOWRISK1 > 1]

Would you be more willing to change your screening practices if it was the radiologist, who reads your mammograms, who recommended that you reduce your screening frequency?

[IF NECESSARY, SAY: By radiologist, we mean a specialized doctor who reads your mammogram and sends you a letter explaining the results.]

- 1 DEFINITELY
- 2 PROBABLY
- 3 PROBABLY NOT
- 4 DEFINITELY NOT
- 5 DON'T KNOW/REFUSED

{Q: LOWRISK4}

If your insurance company was willing to cover a mammogram every year, but the new guidelines recommended that you only have one every two years, would you be willing to have one every two years?

- 1 DEFINITELY
- 2 PROBABLY
- 3 PROBABLY NOT
- 4 DEFINITELY NOT
- 5 DON'T KNOW/REFUSED

{Q: LOWRISK5}

In your opinion, what would be some of the potential disadvantages of reducing your frequency of breast cancer screening? (SELECT ALL THAT APPLY)

- 1 DELAYED/TOO LATE DETECTION OF BREAST CANCER
- 2 INCREASED WORRY/FEAR BETWEEN SCREENINGS
- 3 CRITICISM FROM FAMILY/FRIENDS
- 4 NONE
- 5 DON'T KNOW/REFUSED

{Q: LOWRISK6}

In your opinion, what would be some of the potential advantages of reducing your frequency of breast cancer screening?

- 1 REDUCED COST
- 2 LESS HASSLE FROM INSURANCE COMPANIES

- 3 LESS FREQUENT ANXIETY WHILE WAITING FOR RESULTS
- 4 FEWER UNECESSARY MEDICAL PROCEDURES
- 5 FEWER FALSE POSITIVES
- 6 REDUCED EXPOSURE TO RADIATION
- 7 FEWER TRIPS TO THE DOCTOR/HOSPITAL
- 8 FEWER PAINFUL OR UNCOMFORTABLE EXAMINATIONS
- 9 FEWER EMBARRASSING OR UNPLEASANT EXAMINATIONS
- 10 NONE
- 11 DON'T KNOW/REFUSED

[IF ROUTINE = 1 OR 2 (EVERY 6 MONTHS OR YEARLY) SKIP TO HIRISK1B]

{Q: HIRISK1a}

IF APPLICABLE: Now let's think about the opposite situation.

Suppose that, based on these new tailored recommendations, your health care provider advised you to have a mammogram more often than you currently do. Would you be willing to increase your frequency of breast cancer screening?

IF NO PCP OR GYN, SAY: Suppose you were so advised by a health care practitioner.

- 1 DEFINITELY
- 2 PROBABLY
- 3 PROBABLY NOT
- 4 DEFINITELY NOT
- 5 DON'T KNOW/REFUSED

{Q: HIRISK2a}

[ASK IF HIRISK1a = 3 OR 4]

Why might you be unwilling to increase your frequency of breast cancer screening?
(SELECT ALL THAT APPLY)

- 1 CONCERNS ABOUT COST
- 2 NOT RECOMMENDED BY A DOCTOR
- 3 MISTRUST OF GUIDELINES/RECOMMENDATIONS
- 4 CONCERNS ABOUT RADIATION EXPOSURE
- 5 HABIT
- 6 CONCERNS ABOUT HASSLE/INCONVENIENCE
- 7 DIFFICULTY ACCESSING HEALTH CARE SERVICES
- 8 FALSE POSITIVES
- 9 NO FAMILY HISTORY
- 10 ALREADY HAVE VERY FREQUENT SCREENINGS

- 11 OTHER [SPECIFY]
- 12 DON'T KNOW/REFUSED

{Q: HIRISK3a}

[ASK IF HIRISK1A > 1]

Would you be more willing to change your screening practices if it was the radiologist, who reads your mammograms, who recommended that you increase your screening frequency?

[IF NECESSARY, SAY: By radiologist, we mean a specialized doctor who reads your mammogram and sends you a letter explaining the results.]

- 1 DEFINITELY
- 2 PROBABLY
- 3 PROBABLY NOT
- 4 DEFINITELY NOT
- 5 DK/REF

{Q: HIRISK4a}

In your opinion, what would be some of the potential disadvantages of increasing your frequency of breast cancer screening? (SELECT ALL THAT APPLY)

- 1 INCREASED COST
- 2 INCREASED HASSLE FROM INSURANCE COMPANIES
- 3 MORE FREQUENT ANXIETY WHILE WAITING FOR RESULTS
- 4 MORE UNECESSARY MEDICAL PROCEDURES
- 5 MORE FALSE POSITIVES
- 6 INCREASED EXPOSURE TO RADIATION
- 7 MORE TRIPS TO THE DOCTOR/HOSPITAL
- 8 UNPLEASANT EXAMINATIONS MORE OFTEN
- 9 NONE
- 10 DON'T KNOW/REFUSED

{Q: HIRISK5a}

In your opinion, what would be some of the potential advantages of increasing your frequency of breast cancer screening?

- 1 EARLIER DETECTION OF BREAST CANCER
- 2 DECREASED WORRY/FEAR BETWEEN SCREENINGS
- 3 APPROVAL FROM FAMILY/FRIENDS
- 4 NONE
- 5 DON'T KNOW/REFUSED

{Q: HIRISK1b}

If, based on these new tailored recommendations, your health care provider advised to have a breast cancer screening test other than a mammogram (such as an MRI or ultrasound), would you be willing to change the type of breast cancer screening you receive?

IF NO PCP OR GYN, SAY: Suppose you were so advised by a health care practitioner.

- 1 DEFINITELY
- 2 PROBABLY
- 3 PROBABLY NOT
- 4 DEFINITELY NOT
- 5 DON'T KNOW/REFUSED
- 6 DOES NOT APPLY (ALREADY RECEIVE ALTERNATIVE SCREENING)

{Q: HIRISK2b}

[ASK IF HIRISK1b = 3 OR 4]

Why might you be unwilling to change your type of breast cancer screening? (SELECT ALL THAT APPLY)

- 1 CONCERNS ABOUT COST
- 2 NOT RECOMMENDED BY A DOCTOR
- 3 MISTRUST OF GUIDELINES/RECOMMENDATIONS
- 4 HABIT
- 5 CONCERNS ABOUT HASSLE/INCONVENIENCE
- 6 DIFFICULTY ACCESSING HEALTH CARE SERVICES
- 7 CONCERNS ABOUT EFFECTIVENESS OF ALTERNATIVE SCREENING METHODS
- 8 FEAR, CLAUSTROPHOBIA
- 9 OTHER [SPECIFY]
- 10 DON'T KNOW/REFUSED

{Q: HIRISK3b}

[ASK IF HIRISK1B > 1]

Would you be more willing to change your screening practices if it was the radiologist, who reads your mammograms, who recommended that you change your type of screening?

[IF NECESSARY, SAY: By radiologist, we mean a specialized doctor who reads your mammogram and sends you a letter explaining the results.]

- 1 DEFINITELY
- 2 PROBABLY

- 3 PROBABLY NOT
- 4 DEFINITELY NOT
- 5 DON'T KNOW/REFUSED

{Q: HIRISK4b}

If your insurance company was willing to cover an ultrasound or MRI once a year, in addition to an annual mammogram, and the new guidelines recommended that you receive one that often, would you be willing to have an ultrasound or MRI in addition to a mammogram?

- 1 DEFINITELY
- 2 PROBABLY
- 3 PROBABLY NOT
- 4 DEFINITELY NOT
- 5 DON'T KNOW/REFUSED

{Q: HIRISK5b}

In your opinion, what would be some of the potential disadvantages of changing the type of breast cancer screening you receive? (SELECT ALL THAT APPLY)

- 1 INCREASED COST
- 2 MORE UNECESSARY MEDICAL PROCEDURES
- 3 MORE FALSE POSITIVES
- 4 UNCERTAINTY ABOUT EFFECTIVENESS OF ALTERNATIVE METHODS
- 5 INCREASED HASSLE/INCONVENIENCE
- 6 GREATER DIFFICULTY ACCESSING HEALTH CARE SERVICES
- 7 NONE
- 8 DON'T KNOW/REFUSED

{Q: HIRISK6b}

In your opinion, what would be some of the potential advantages of changing the type of breast cancer screening you receive?

- 1 EARLIER DETECTION OF BREAST CANCER
- 2 DECREASED WORRY/FEAR BETWEEN SCREENINGS
- 3 DECREASED EXPOSURE TO RADIATION
- 4 FEWER UNPLEASANT EXAMINATIONS
- 5 NONE
- 6 DON'T KNOW/REFUSED

{Q: NEED2KNO}

The new recommendations might ask women to change when they are screened or how they are screened. We are interested in how you would make a decision about that. What types of information would you need to have before making a decision about changing your screening practices? [OPEN END]

NOTE: CODING CATEGORIES ARE BASED ON FOCUS GROUP RESPONSES.

- 1 RISKS, SAFETY
- 2 COSTS, INSURANCE
- 3 DISCOMFORT, PAIN
- 4 RESEARCH, EVIDENCE
- 5 TAILORED/PERSONAL INFORMATION
- 6 ADVICE OF DOCTOR
- 7 ADVICE OF RADIOLOGIST
- 8 COMPARISON WITH OLD RECOMMENDATIONS
- 9 OTHER

H. INFORMATION SOURCES

We're nearing the end of the interview now. The next questions are about sources of information about breast cancer and breast cancer screening.

{Q: LOOKINFO}

Imagine for a moment that you needed to get information about breast cancer risk or about breast cancer screening. Where would you go to look for this information?
(CHECK ALL THAT APPLY, CODE FROM RESPONSE, PROMPT FOR CLARITY)

- 1 HEALTH CARE PROFESSIONAL (DOCTOR, NURSE, PHARMACIST ETC.)
- 2 PAMPHLETS PROVIDED IN DOCTOR'S OFFICE OR HOSPITAL
- 3 FAMILY AND/OR FRIENDS
- 4 PASTOR OR SPIRITUAL ADVISOR
- 5 PATIENT SUPPORT GROUP
- 6 TELEVISION OR RADIO
- 7 NEWSPAPERS OR MAGAZINES
- 8 BOOKS
- 9 MEDICAL JOURNALS
- 10 MEDICAL SPONSOR WEBSITE (NIH, WEBMD ETC)
- 11 OTHER INTERNET WEBSITE
- 12 SOCIAL MEDIA, (FACEBOOK, TWITTER ETC)
- 13 OTHER [SPECIFY]
- 14 DON'T KNOW
- 15 REFUSED

{Q: INTERNET}

How often do you access the Internet, either with a computer, tablet or smart phone?
Would you say every day, several times a week, once a week, or less often?

- 1 EVERY DAY
- 2 SEVERAL TIMES A WEEK
- 3 ONCE A WEEK
- 4 LESS THAN ONCE A WEEK

5 DK/REF

{Q: FACEBOOK}

[ASK IF INTERNET < 4]

Are you a regular user of social media such as Facebook or Twitter?

IV: REGULAR = ONCE A WEEK OR MORE

- 1 YES
- 2 NO
- 3 DK/REF

{Q: SOCMEDIA}

[ASK IF INTERNET < 4]

Have you ever received any information about breast cancer risk or screening through social media such as Facebook or Twitter?

- 1 YES
- 2 NO
- 3 DK/REF

{Q: TYPMEDIA}

[ASK IF SOCMEDIA = 1]

What kinds of information about breast cancer risk or screening have you received through social media? (SELECT ALL THAT APPLY)

- 1 INFORMATION ABOUT FRIEND/FAMILY SCREENING PRACTICES OR OUTCOMES
- 2 DESCRIPTIONS OF DIFFERENT SCREENING OPTIONS
- 3 ADVICE ABOUT HOW TO PERFORM A BREAST SELF-EXAMINATION
- 4 INFORMATION ABOUT RECOMMENDATIONS OR GUIDELINES
- 5 DESCRIPTIONS OF BREAST CANCER RISK FACTORS
- 6 STATISTICS ABOUT BREAST CANCER
- 7 INFORMATION ABOUT CAMPAIGNS/CHARITIES DEDICATED TO BREAST CANCER RESEARCH/TREATMENT
- 8 INFORMATION ABOUT LOCAL DOCTORS OR HOSPITALS
- 9 OTHER [SPECIFY]
- 10 DK/REF

I. DEMOGRAPHICS

{Q: OUTRO}

There are just a few final questions that we use for statistical purposes only. As before, all of your answers are strictly confidential, and you can skip any questions you don't wish to answer. The first few are about factors that might affect your health.

IF NECESSARY: No names or other identifying information are attached to the data we collect.

{Q: CHILDREN}

Have you given birth to any children?

- 1 YES
- 2 NO
- 3 DK/REF

{Q: BRSTFED}

[ASK IF CHILDREN=1]

Did you breastfeed any of your children?

- 1 YES
- 2 NO
- 3 DK/REF

{Q: SMOKENOW}

Are you currently smoking cigarettes, pipes, cigars, or using tobacco products or have you used any of these within the past three months?

- 1 YES, CIGARETTES
- 2 YES, PIPES/CIGARS
- 3 YES, OTHER TOBACCO PRODUCTS
- 4 NO
- 5 DK/REF

{Q: SMOKEEVR}

[ASK IF SMOKENOW > 1]

Have you smoked at least 100 cigarettes in your life?

- 1 YES
- 2 NO
- 3 DK/REF

{Q: INSURE}

Now I would like to ask you about any health insurance you currently have that helps pay for the cost of health care. I'm going to read a list of a few types of health insurance, and I'd like you to tell me which of these you have, if any. Are you personally covered by...

[CHECK ALL THAT APPLY]

- 1 Private health insurance offered through an employer or union
- 2 A private health insurance plan that you bought yourself
- 3 Medicaid or some other type of state medical assistance for low-income people
- 4 Medicare, the government program that pays health care bills for people over age 65 and for some disabled people
- 5 Health insurance through any other source, including military or veteran's coverage

- 6 Don't have any kind of insurance
- 7 DON'T KNOW
- 8 REFUSED

{Q: ZIPCODE}

What is the zip code for where you currently live?

{Q: CELLCOMP}

[ASK IF CELLLAND = 2 AND OWNCCELL = 1 OR CELLLAND=1 AND HAVELINE = 1 (HAS BOTH CELL AND LANDLINE)]

You mentioned before that you have a regular telephone at home. Thinking about ALL the telephone calls that you and other members of your household make and receive, would you say that . . .

- 1 Almost all are on a landline phone
- 2 Most of them are on a landline phone
- 3 Amount of calls on a landline and cell phone are about equal
- 4 Most of the calls are on a cell phone
- 5 Almost all of them are on a cell phone
- 6 DON'T KNOW/UNABLE TO RATE
- 7 REFUSED

{Q: PHONE1A}

[ASK IF HAVELINE=1 (YES)]

Our center is doing some research on listed and unlisted telephone households. As far as you know, is the landline or regular phone for your household listed in the current telephone book?

- 1 YES
- 2 NO
- 3 DON'T KNOW
- 4 REFUSED

{Q: PHONE1B}

[ASK IF CELLLAND=2 (REGULAR OR LANDLINE PHONE)]

Our center is doing some research on listed and unlisted telephone households. As far as you know, is the number I dialed listed in the current telephone book?

- 1 YES
- 2 NO
- 3 DON'T KNOW
- 4 REFUSED

{Q: PHONE2}

[ASK IF PHONE1A = 2 OR PHONE1B = 2)]

Is the number not in the phone book because you chose to have an unlisted number, or because you got this number after the current phone book came out?

- 1 UNLISTED OR UNPUBLISHED
- 2 GOT NUMBER AFTER PHONE BOOK CAME OUT
- 3 OTHER [SPECIFY]
- 4 DON'T KNOW
- 5 REFUSED

{Q: OWNHOME}

Do you currently own or rent your home?

- 1 Yes
- 2 No
- 3 DON'T KNOW/NOT SURE

{Q: MARITAL}

Are you currently...

- 1 married,
- 2 widowed,
- 3 divorced,
- 4 separated, or
- 5 have never been married?

{Q: EMPSTAT}

What is your current employment status? Are you...(READ LIST)

- 1 Working full time
- 2 Working part time
- 3 Unemployed, laid off or looking for work
- 4 With a job, but not at work because of temporary illness, vacation or strike
- 5 Retired
- 6 Going to school
- 7 Homemaker/stay at home mom/keeping house
- 8 OTHER [SPECIFY]
- 9 DON'T KNOW/REFUSED (VOLUNTEERED)

{Q: YRBORN}

In what year were you born?

ENTER YEAR HERE 19__ AND PRESS RETURN
TYPE 2 DIGITS ONLY!

[ENTER "00" FOR YEAR PRIOR TO 1900; ENTER "99" FOR REFUSED]

{Q: EDUC}

And what is the highest grade or year of regular school that you have completed?

(DO NOT READ LIST)

- 1 NO FORMAL SCHOOLING
- 2 8TH GRADE OR LESS

- 3 SOME HIGH SCHOOL
- 4 HIGH SCHOOL DIPLOMA
- 5 G.ED.
- 6 SOME COLLEGE
- 7 2-YEAR DEGREE
- 8 TECHNICAL OR TRADE SCHOOL
- 9 BACHELOR'S DEGREE
- 10 GRADUATE OR PROFESSIONAL SCHOOL
- 11 DON'T KNOW/REFUSED (VOLUNTEERED)

{Q: HSINCM}

I am going to read a list of income ranges. Please stop me when I read the range that best describes your annual household income from all sources before taxes and other deductions.

- 1 LESS THAN \$10,000
- 2 \$10,000-\$14,999
- 3 \$15,000-\$19,999
- 4 \$20,000-\$29,999
- 5 \$30,000-\$49,999
- 6 \$50,000-\$74,999
- 7 \$75,000-\$99,999
- 8 \$100,000-\$149,999
- 9 \$150,000+
- 10 DON'T KNOW
- 11 REFUSED

{Q: HISPANIC}

Are you, yourself, of Hispanic origin or descent, such as Mexican, Puerto Rican, Cuban or some other Latin American background?

- 1 Yes
- 2 No
- 3 DK/REF

{Q: ASHKENAZ}

Are you of Ashkenazi Jewish descent?

IF NECESSARY, SAY: Ashkenazis are descended from the Jewish people of Eastern and Central Europe.

- 1 Yes
- 2 No
- 3 DK/REF

{Q: RACE}

Which of the following categories best describes your race? [READ LIST – ENTER ALL THAT APPLY]

- 1 White

- 2 Black, African American
- 3 Asian or Pacific Islander
- 4 American Indian, Eskimo, Aleut
- 5 Mixed Race (Specify) _____
- 6 Other [SPECIFY]
- 7 (VOL) DK/REF _____

{Q: INVITE}

Have you recently been asked to participate in a medical study at UVa to develop tailored recommendations for breast cancer screening?

- 1 YES
- 2 NO
- 3 DK/REF

IV, IF NECESSARY: We are not recruiting for that study. It is only open to women who had a mammogram at UVa during a certain time period. If you are interested in participating, please call ### for more information.

{Q: PARTIC}

[ASK IF INVITE=1]

Are you currently an active participant in the study?

- 1 YES
- 2 NO
- 3 DK/REF

J. CONCLUSION

{Q: THANKYOU}

We are now finished with the questionnaire. I would like to thank you very much for your participation. If you have questions or concerns about the survey, you can contact us at 1-800-CSR-POLL or Assistant Director Robin Bebel at 434-982-5541.